

FACT SHEET

AUTISM IS PREVALENT:

1 in 166 children are diagnosed with an autism spectrum disorder
(CDC, 2004)

What is Autism?

Autism is a biologically-based disorder that affects the development and functioning of a person's verbal and non-verbal communication skills, social interaction and patterns of behavior. There is no identified cause for autism nor is there an identified "cure" for autism.

Theories of the etiology of autism include genetics, infectious diseases, prenatal or postnatal trauma, immune system deficiencies and metabolic disorders. There is no cure for autism and the majority of children and adults with autism will require a lifetime of supportive services (Holmes, 1997). Studies show that early detection and intervention can have significant effects on the progress and functioning level of the children. "There is not a simple direct relationship, however, between any particular current intervention and recovery from autism" (National Research Council, 2001, p.43).

The definition of "autism" has changed little since it was coined by Leo Kanner in 1943, but the terminology used today to describe the disorder has. The terms Pervasive Developmental Disorder, Autism Spectrum Disorder, Autistic Spectrum Disorder and autism essentially describe the same disorder: significant impairments in the areas of socialization, communication and behavior that manifest early development.

The standard diagnostic criteria is defined by the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR) (2000) published by the American Psychiatric Association. In the DSM-IV-TR, under the diagnostic category Pervasive Developmental Disorder (PDD), are the specific criteria for a diagnosis of *Autistic Disorder*, *Asperger's Disorder*, *Rett's Disorder*, *Childhood Disintegrative Disorder*, and *Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)*.

"The manifestations of autism vary considerably across children and within an individual child over time. There is no single behavior that is always typical of autism and no behavior that would automatically exclude an individual child from a diagnosis of autism, even though there are strong and consistent commonalities, especially relative to social deficit" (National Research Council, 2001). For these reasons, the term *Autism Spectrum Disorder (ASD)* has been widely adopted in the professional literature because it more accurately describes the continuum of symptom severity and is inclusive of people with varying diagnoses.

How many people have an Autism Spectrum Disorder?

According to the Centers for Disease Control and Prevention CDC (2004) 1 in 166 children are diagnosed with an autism spectrum disorder. In the United States

alone, there are over 1.5 million Americans with autism. It is estimated that in New Jersey between 12,000 and 18,000 people have an autism spectrum disorder.

How is it diagnosed?

Currently there are no biological markers or “tests” that detect autism. Clinicians make a diagnosis based on parental reports along with clinical observations of the child. Autism is found in all races, ethnicities and socio-economic groups. Autism is four times more prevalent in boys than girls. The national average age of diagnosis is between the ages of 3 and 4, even though a reliable diagnosis can be made by age 2. In addition to the DSM-IV-TR, tools for assessing a child for autism spectrum disorders include the Autism Diagnostic Observation Scales (ADOS; Lord et al., 2000) the Autism Diagnostic Interview-Revised (ADI-R; Lord et al. 1994) and the Childhood Autism Rating Scales (CARS; Schopler et al., 1988).

Some signs and symptoms associated with ASD include but *are not limited to*:

- Little or no eye contact;
- No babbling, pointing or meaningful gestures by 1 year of age;
- No single words by age 16;
- Loss of language or other skills at any age;
- Lack of pretend, imitative and functional play appropriate to developmental age;
- Unusual or inappropriate fears;
- Failure to develop peer relationships appropriate to developmental age; and
- Stereotypical and repetitive behavior.

What should I do if I suspect my child has an autism spectrum disorder?

If you are the parent or guardian of a child and are concerned about his/her development, your family physician can offer further information and referrals to specialists in your area who are qualified to make a diagnosis. If your child is aged 0-3, he/she may be eligible for Early Intervention Services. For school age children (3-21) Special Education is provided for students through the local school district.

What is New Jersey doing about autism?

New Jersey has been a leader in the field of autism for almost four decades.

- Continuing in that tradition, in 2003 Governor McGreevey signed into law A-2601 creating a permanent source of funding for research into the causes, diagnosis and prevention, control and treatment of autism in New Jersey. The funds will go to the Governor’s Council for Medical Research and Treatment of Infantile Autism. The Council was created in 1999.
- One of the county’s oldest advocacy agencies for people with autism, The New Jersey Center for Outreach and services for the Autism Community (COSAC) is located in Ewing, NJ. Established in 1965, COSAC offers parent and professional training programs, a toll-free Information and Referral Line, parent support groups, advocacy assistance, public awareness initiatives, legislative programs and more.
- There is established at the University of Medicine and Dentistry- New Jersey Medical School, the Autism Center. The objectives of the Autism Center are

to research the biological pathways of ASD, research safe and effective treatments and to provide outreach and support to individuals with autism and their families and healthcare professionals.

- The New Jersey Medical School has partnered with the CDC, the New Jersey Department of Education and the Governor's Council on Autism to conduct The New Jersey Autism Study. The goals of this study are determine and monitor the number of children in NJ with an ASD.
- Researchers at the Center for Childhood Neurotoxicology and Exposure Assessment of UMDNJ and Rutgers University are studying the interaction between environmental chemical and the expression of autism in 24-36 month old children.
- The New Jersey Early Intervention System published Service Guidelines for Children with Autism Spectrum Disorders in July 2003. These service guidelines are to assist families and providers in designing appropriate intervention services based on best practice research.
- The national headquarters for The National Alliance for Autism Research (NAAR) is located in Princeton.

The following is a partial list of state and national resources that provide information on autism spectrum disorders. The inclusion of a website in this list does not explicitly nor implicitly imply endorsement of the organization, its philosophy or of the information contained in the site.

State & National Links

Adult Services in New Jersey <http://www.state.nj.us/humanservices/ddd/index.html>

Autism Research Institute www.autism.com/ari/

Autism Society of America www.autism-society.org

Cure Autism Now www.can.org

National Institutes of Health (NIH) www.nih.gov

New Jersey Protection and Advocacy www.njpanda.org

Statewide Parent Advocacy Network (SPAN) www.spannj.org

Web links from the text:

1. National Research Council -
<http://books.nap.edu/openbook/0309072697/html/index.html>
2. DSM IV-TR <http://www.autism-biomed.org/dsm-iv.htm>
3. Center for Disease Control and Prevention (CDC)
www.cdc.gov/ncbddd/dd/ddautism.htm
4. Early Intervention Services - <http://www.state.nj.us/health/fhs/eiphome.htm>
5. Special Education – <http://www.nj.gov/njded/specialed/>
6. New Jersey's Governors Council on Autism
www2.umdnj.edu/chinjweb/govcofolder.htm
7. COSAC – www.njcosac.org
8. The New Jersey Autism Study - <http://www.cdc.gov/ncbddd/dd/aic/states/nj.htm>
9. Center for Childhood Neurotoxicology and Exposure Assessment -
<http://www.eohsi.rutgers.edu/childhood/index.shtml>
10. Service Guidelines for Children with Autism Spectrum Disorders -
<http://www.state.nj.us/health/fhs/autism.htm>
11. The National Alliance for Autism Research (NAAR) – www.naar.org